

NEWSLETTER
#2
FEBRUARY 2022

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*Dear friends
and partners,*

This is the second edition of the biannual newsletter of the United Nations Mandate of the Special Rapporteur on the Elimination of Discrimination Against Persons Affected by Leprosy and their Family Members.

Since June 2021, when I shared the first newsletter with you, I have presented two thematic reports – [Disproportionate impact of the coronavirus disease \(COVID-19\) pandemic on persons affected by leprosy and their family members: root causes, consequences and the way to recovery](#), presented to the UN Human Rights Council (HRC), and [An unfinished business: Discrimination in law against persons affected by leprosy and their family members](#), presented to the UN General Assembly. In addition to that, I started the process of writing my next thematic report, on the right to the highest attainable standard of physical and mental health for persons affected by leprosy / Hansen's disease and their family members, to be presented at the 50th session of the HRC, in June, 2022.

Again, back in January, the discussion on terminology has reappeared when the Brazilian Federal Court prohibited the Federal Government and the President of Brazil, Mr. Jair Bolsonaro, from using discriminatory language when referring to Hansen's disease. Such decision came as a response to a lawsuit filed by the national movement of persons affected by Hansen's disease – MORHAN – against the discriminatory use of the word leprosy by the President of Brazil. As [I have reported after my official visit to Brazil](#), the words leprosy and its derivatives were prohibited by a Federal Law (9.010) in 1995. In Brazil, the official nomenclature for the disease is hanseníase (Hansen's disease, in English).

Discrimination on the grounds of leprosy / Hansen's disease is very much related to harmful stereotypes about the disease. Such harmful stereotypes are usually framed by derogatory language. In my last report to the General Assembly, I took note of how many of the existing discriminatory legal frames against persons affected by leprosy/Hansen's disease make use of derogatory language.

Without a doubt, promoting dignifying language in relation to leprosy / Hansen's disease is key to eliminating discrimination. I congratulate MORHAN for such an important victory. As I have said over and over again, world leaders must stop misusing the word leprosy because its widespread use as a metaphor for all that is loathsome contributes to violations of the human rights of persons who experience the disease. I have also had very recently a negative experience in which my use of the term leprosy led to the violating misuse of the term "leper" by a journalist. Such negative experience made me think that, perhaps, we may need to abandon the term leprosy altogether. I believe it is urgent for the community to hold a big discussion about terminology in which persons who have experienced leprosy / Hansen's disease and their representative organizations can decide which terms are appropriate when naming the disease and the people who experience it. I urge international organizations to create the opportunities for such a discussion to happen. Considering all this and until a final decision is made by the primary stakeholders, that is, persons who have experienced leprosy / Hansen's disease, allow me to personally favor the term Hansen's disease. The terminology employed in this newsletter respects the context in which it was used: the official name of the event or document mentioned, the country to which I refer to, etc.

Here you will find news about some of my work, but also about key activities and victories from civil society organizations and, in particular, organizations of persons affected by Hansen's disease. It should be noted that both the work of my mandate, and that of civil society organizations, has suffered a great impact due to the crisis brought on by the Covid-19 pandemic. While such crisis is still with us, allow me to recall the importance of a fair and equitable access to vaccines against Covid-19, especially in the countries of the Global South, where Hansen's disease is endemic.

Despite the challenging times we live, our determination to free the world from discrimination on the grounds of Hansen's disease and all its intersections (gender, disability, age, race, among others) persists. With a big appreciation to the wonderful work that is being done by all of you, I urge us all to continue cooperating and working together to rebuild a world in which no-one is left behind.

Happy reading!

“END SHAMEFUL LEPROSY DISCRIMINATION IN LAW”:

The core recommendation of my report to the UN General Assembly...

An unfinished business: discrimination in law against persons affected by leprosy and their family members (A/76/148) -- This is my first report submitted to the United Nations General Assembly, where I identified more than 100 laws that discriminate against persons affected by Hansen’s disease worldwide, in at least 30 countries. The report also addresses: their roots in biomedical misconceptions about the disease; their provisions and consequences, which are reflected in the persisting dehumanization of persons who have experienced Hansen’s disease and their family members; the efforts undertaken towards legal harmonization; and the impact of discrimination in law against persons affected by leprosy based on the lived experience of the individuals concerned.

By formalizing harmful stereotypes as lawful labels and normalizing humiliation and violence as authorized practices, such laws significantly compromise livelihoods, exclude persons who have experienced Hansen’s disease from political and civic participation, and augment the State’s negligence towards this marginalized group, especially women.



That’s why it is urgent to finish the business of formal recognition of persons affected by Hansen’s disease as rights holders. In the report, I make constructive recommendations for eliminating discriminatory laws, customs and practices, as well as for fighting against some of the more immediate consequences of extended discrimination in law with regard to the enjoyment of rights and access to opportunities of persons affected by Hansen’s disease and their family members on an equal basis with others.

 [READ THE FULL REPORT](#)

 [READ THE FACTSHEET](#)

...it was also my main appeal on World Leprosy Day

Faced with the urgency of eliminating these discriminatory laws, my statement for World Leprosy Day, celebrated this year on January 30, makes a direct appeal to states to end shameful leprosy discrimination in law.

“It is time for all States concerned to make a choice: whether to keep such discriminatory laws against persons affected by leprosy in violation of international human rights standards, or to eliminate such discrimination in law without delay”



 [READ THE STATEMENT](#)

Speaking about putting an end to discriminatory laws... Good news from India: The National Human Rights Commission has urged the Centre, states and Union Territories to remove discriminatory legal provisions against persons affected by Hansen’s disease in the laws of the country.

[CHECK OUT THE FULL ARTICLE](#) 

MORE ABOUT THE THEMATIC REPORTS

"OTHER PEOPLE'S PROBLEMS" ARE EVERYONE'S PROBLEMS: Check out the presentation and factsheet of my previous report

As I wrote to you in the newsletter number 1, my report submitted in mid-2021 to the UN Human Rights Council carried the following message: "There is no building back better if States fail to put those who have been systematically pushed further behind at the centre of recovery efforts". This thematic report addresses the disproportionate impact of the coronavirus disease (COVID-19) pandemic on persons affected by leprosy / Hansen's disease and their family members. In addition to accessing the [document in several languages](#), now you can also watch the [video](#) of the report presentation to the HRC (on July 1st) and read the [factsheet](#) with its key points.

Report on the right to health in process

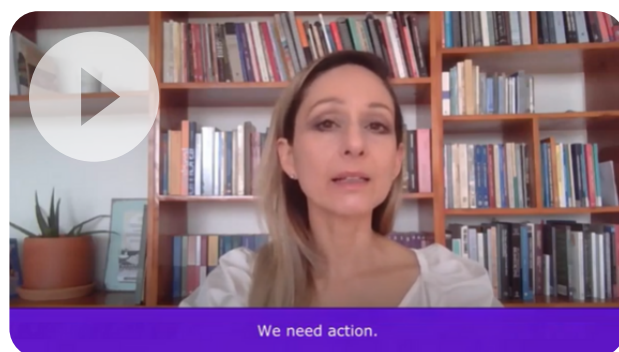
At the 50th session of the Human Rights Council, I will present my next thematic report on the right to the highest attainable standard of physical and mental health for persons affected by Hansen's disease and their family members, on which I am currently working on. I take the opportunity to thank all the States, Civil Society Organizations and individuals who have contributed with key information to this report. I also wish to thank particular organizations and groups, such as the Sasakawa Health Foundation The Leprosy Mission International and IDEA International, but also individuals like Deepa Palaniappan, that have provided me with valuable support in the preparation and dissemination of my consultations to States, Civil Society Organizations and individuals. The report will be public around the time of my presentation to the Human Rights Council next July.

COOPERATION WITH OTHER HUMAN RIGHTS MECHANISMS,
KEY STAKEHOLDERS AND INTERGOVERNMENTAL AGENCIES

"WE NEED ACTION"

My speech at the World Leprosy and World Neglected Tropical Diseases Day

On 26, January, 2022, the World Health Organization (WHO) organized a high-level virtual event to celebrate World Leprosy and Neglected Tropical Diseases Day under the topic "Achieving health equity to end the neglect of poverty-related diseases". I had the great honor of participating in this important event together with the Secretary-General of the United Nations, Mr. António Guterres; the WHO Goodwill Ambassador for Universal Health Coverage, Mr. Keizo Takemi; the Permanent Representative of India to the United Nations, Ambassador T. S. Tirumurti; and the Director-General of the World Health Organization, Dr. Tedros Adhanom Ghebreyesus.



**Discrimination is, indeed, the key to understanding both
the underlying causes and the harmful effects of NTDs.
It is time to put a stop to this!**

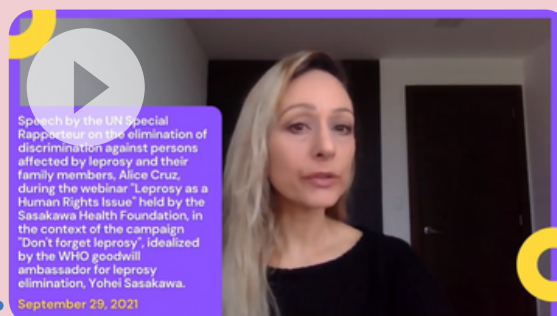
On World Leprosy and Neglected Tropical Diseases Day, my thoughts went to those who experience leprosy / Hansen's disease and other NTDs and I celebrated the resilience with which people who experience NTDs fight its devastating consequences, survive and support their peers. Their fight is the fight against endemic social injustice.

I wish to thank Dr. Pemmaraju Venkata Ranganadha Rao for his wonderful cooperation as Acting Team leader of the Global Leprosy Programme.

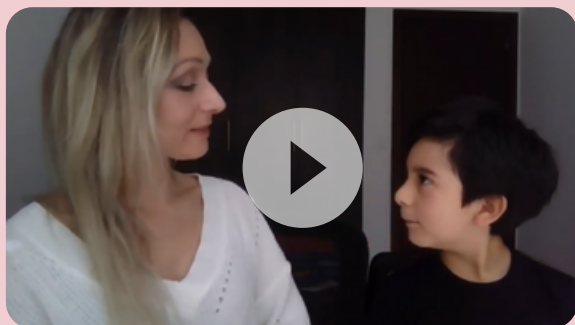
Don't forget leprosy global campaign

At the occasion of the 20th anniversary of the appointment of Mr. Yohei Sasakawa as the WHO Goodwill Ambassador for Leprosy Elimination in 2021, the Sasakawa Leprosy (Hansen's disease) Initiative is running a campaign called "Don't forget leprosy." The campaign is designed to send the message that leprosy must not be overlooked amid the COVID-19 pandemic. Here, I share with you my participation in some moments of the campaign:

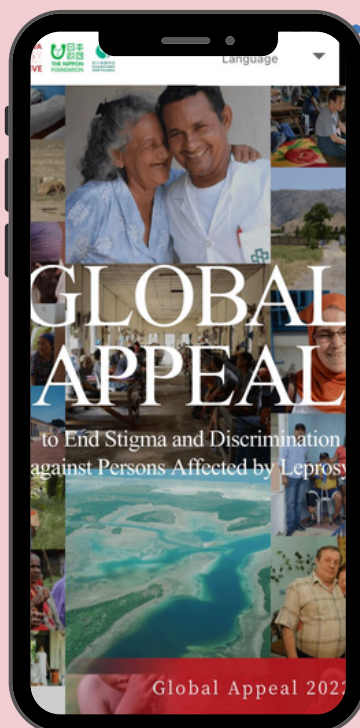
"Empowerment is a collective process and so is systemic change. It is through organized collective action that we can bring the change we want to see in the world" - Check out my full speech during the webinar "Leprosy as a Human Rights Issue" on September 29, 2021.



On 13, January, 2022, I participated in the meeting that launched "Program B" of the campaign, which supports research undertaken by NGOs, organizations of persons affected by Hansen's disease, universities, research institutes, medical associations and other institutions. I congratulate the extraordinary research plans of the organizations and look forward to its results. We urgently need to gather evidence on Hansen's disease-related discrimination and it is critical that systematic data collection involves affected people and their organizations. Such data will be of enormous importance for the work of my mandate.



With the special participation of my son Leo Achik Llasag Cruz, I had the honor to speak in the webinar "Raising Awareness about leprosy: The role of Youth", organized as part of the campaign on January 25, 2022.



The 17th Global Appeal to End Stigma and Discrimination against Persons Affected by Leprosy has been released online. This year, the campaign *Don't forget leprosy* is the central message of the initiative. On the website <https://gasasakawa.org/>, in addition to the webinars on Human and Youth Rights, in which I was honored to participate, you can check out the videos of other debates, the opening ceremony with international high profile people and an exhibition of photos that has persons affected by Hansen's disease as the main protagonists of the interventions related to this campaign.

I invite you to follow this campaign on social media using the hashtags #DontForgetLeprosy or #DontForgetHansensDisease.

Message in the COSP14 side event: It is necessary to ensure the participation of marginalized groups in COVID-19-related plans and recovery

A side event to the 14th session of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities (CRPD) addressed the topic "Work and Employment Situation of Persons Affected by Leprosy amid the Coronavirus Pandemic and Efforts to Resolve the Challenges They Face", organized by Disabled Peoples' International and Sasakawa Health Foundation in partnership with the Permanent Mission of Japan, Permanent Mission of India, Permanent Mission of Portugal, Permanent Mission of Brazil and Global Partnership for Zero Leprosy. The event was held on June 18, 2021.

As a keynote speaker, I emphasized the need for States to ensure the social participation of persons affected by Hansen's disease and other marginalized groups in COVID-19-related plans and recovery.

The COVID-pandemic has brutally revealed how the principle of universality of human rights as provided for in the Universal Declaration of Human Rights has hardly been fulfilled. That is why establishing minimum core obligations of social and economic rights regarding vulnerable groups as a matter of priority, may be a necessity now more than ever, together with anti-discriminatory policies that ensure the enjoyment of rights without discrimination.



[READ MY SPEECH](#)



[WATCH THE FULL EVENT](#)

PERMANENT DIALOGUE WITH THE ORGANIZATIONS OF PERSONS AFFECTED BY HANSEN'S DISEASE

Morhan mediated meeting with Brazilian civil society



On 24, January , I was received - virtually - by representatives of civil society organizations and activists working to fight discrimination against persons affected by Hansen's disease in Brazil. The meeting was mediated by the Movement for the Reintegration of Persons Affected by Hansen's Disease (MORHAN) and had the participation of Mr. Artur Custodio MH and Mr. Faustino Pinto, national coordinators of MORHAN; Mr. Carlos Nicodemos and Mr. Pedro Peruzzo, volunteer lawyers for the MORHAN's Access to Justice and Human Rights Network; Dr. Claudio Salgado, president of the Brazilian Society of Hansenology (SBH); Dr. Clódis Tavares - national coordinator of RedeHans; DR. Sandra Durães, coordinator of the national Hansen's disease campaign of the Brazilian Society of Dermatology (SBD); Ms. Inez Montagner; Mr. João Victor, MORHAN and RedeHans' volunteers.

PerMaTa now has a website

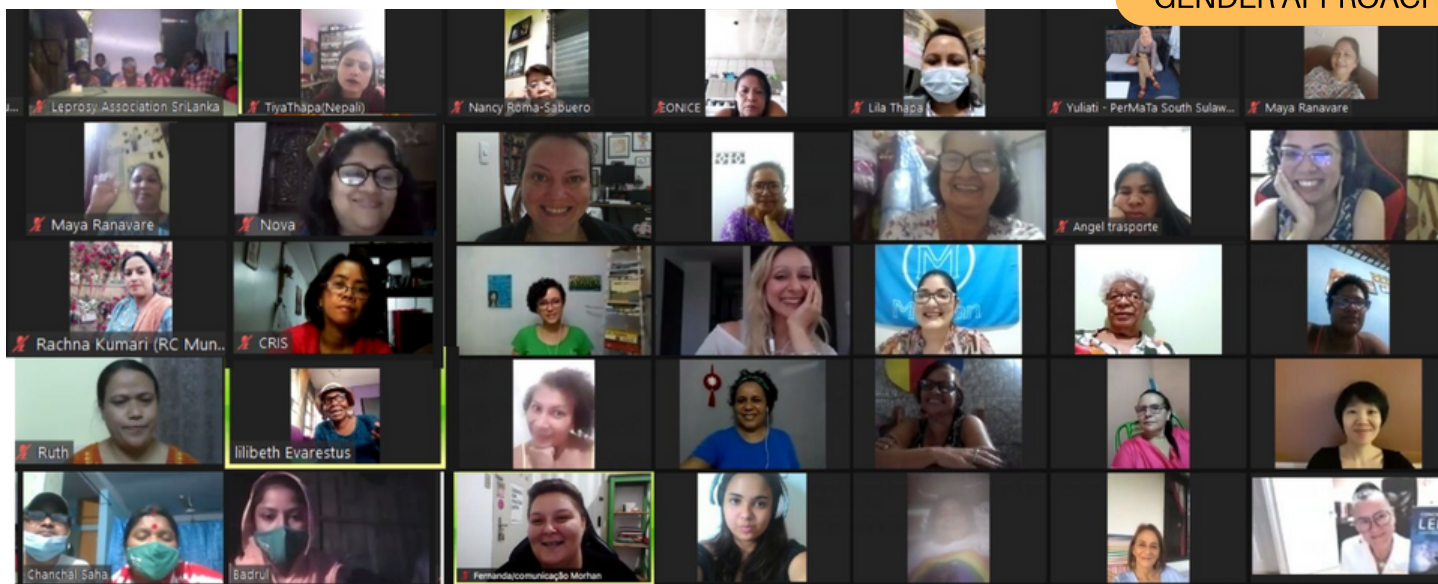
It was with great joy that I participated in the launch of the PerMaTa South Sulawesi's website in August, 2021. PerMaTa is a non-profit organization of persons affected by leprosy / Hansen's disease from Indonesia.

As the organization's representatives said at the launch of the website, information is a key element for raising awareness about leprosy / Hansen's disease. The website is another step forward undertaken by PerMaTa to reach more people and divulge its brilliant work.



WWW.PERMATASULSEL.COM





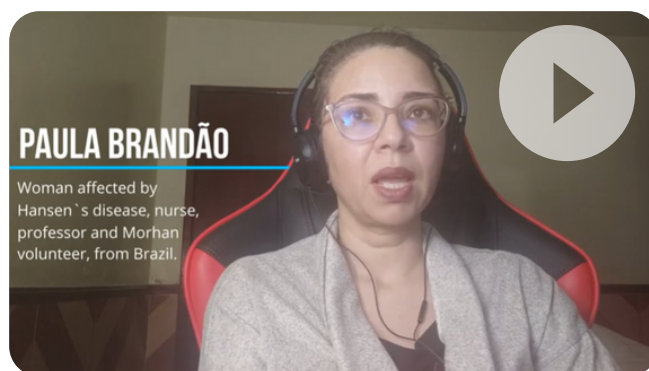
Hansen's disease and the right to health: what girls and women have to say

Between November and December 2021, I had the privilege to participate in three international meetings organized by MORHAN's Women's Policy Department (Brazil) with the goal of listening to girls and women affected by Hansen's disease or female family members of persons affected by the disease. The meetings were divided into three sessions (Americas, Africa and Asia), which gathered 107 women from 15 countries.

Women's experiences and insights are of great importance for the report I am preparing on the right to health and I wish to thank every woman who attended the meetings and particularly women from MORHAN for organizing those.

And speaking of women...

On November 2021, I participated at the meeting organized by Foundation Anesvad "Supporting the comprehensive fight against skin NTDs". As I believe that no discussion can be made without having persons affected by Hansen's disease participating as primary stakeholders, I invited a professor, nurse and woman affected by Hansen's disease, Paula Brandão, to participate together with me. Check out the video!



ENGAGEMENT WITH THE ACADEMIA

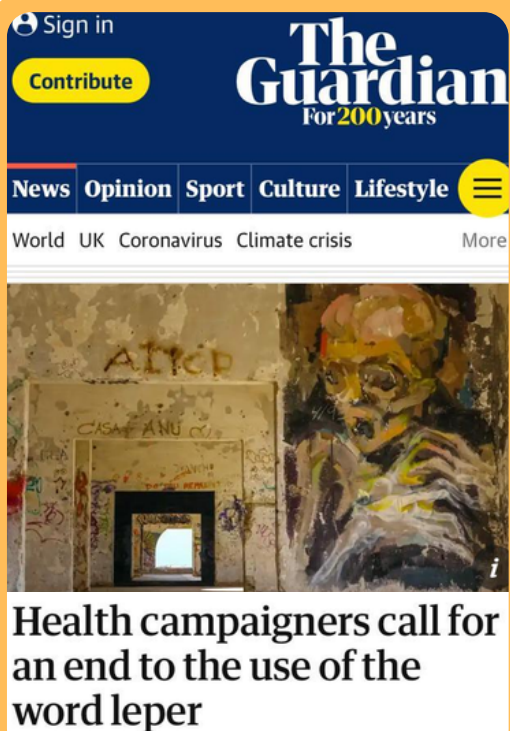
Launch of a researchers and activists' network in Minas Gerais, Brazil

On 8, September, 2021, I had the honor to open the meeting that launched Rede-Hans in the state of Minas Gerais, Brazil, under the topic: "Challenges for enforcing the right of persons affected by Hansen's disease to physical and mental health". Rede-Hans brings together researchers, professors, health workers and activists and, according to its founding manifesto, aims to "promoting the dissemination, integration and production of knowledge and practices that contribute to the production of integral, humanized and ethical care, for the organization and qualification of health services and for the formulation of universal and equitable public policies to approach Hansen's disease in the State of Minas Gerais".



RAISING AWARENESS THROUGH THE PRESS AND SOCIAL MEDIA

The struggle to end discriminatory language related to leprosy/Hansen's disease



On July 2021, The Guardian published the article [“Health campaigners call for an end to the use of the word leper”](#), with a testimony from Mathias Duck, global advocacy manager at The Leprosy Mission International, and information from the reports I presented to the UN HRC.

It is always important to remember that the UN General Assembly approved, in 2010, a resolution accompanied by a set of principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members, which provides that "States must eliminate the discriminatory language, including the derogatory use of the term 'leper' or its equivalent in any language or dialect, of government publications and to quickly review, whenever possible, existing publications that contain this language". I also commented this in a recent article published by a Portuguese speaking press agency ([check it in Portuguese](#)).



How about if we hear the voices of persons affected by Hansen's disease?

I would like to recommend you three videos that have as main protagonists persons affected by Hansen’s disease:

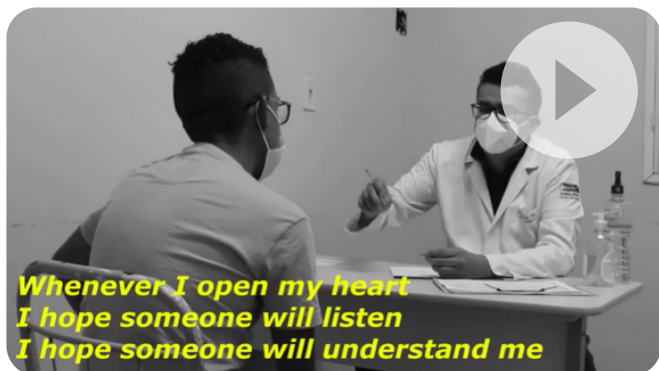


What does dignity mean to you? ILEP Federation and the Global Partnership for Zero Leprosy asked this question to people who have experienced Hansen's disease around the world and the result is this amazing video for the #United4Dignity campaign.

The film "Asha. Stories of leprosy and hope", produced by the Fontilles Foundation in India, has been awarded in the category of gender equality at the SDGs in Action Film Festival 2021 by the United Nations Department of Economic and Social Affairs (UN DESA).



The documentary makes visible the experience of Indian women who have overcome Hansen’s disease stigmatization on its grounds. The film, directed by the Valencian filmmaker Alberto Pla and financed by the Generalitat Valenciana, gathers the testimonies of several women who have experienced Hansen’s disease in India, and shows the work on prevention, treatment, support and socioeconomic inclusion done by Fontilles in this Asian country. A wonderful work portrayed in a fundamental and touching documentary.



“Pedaços / Pieces” is an audiovisual poem written by Faustino Pinto, a person from Brazil who has experienced Hansen’s disease and who is also a member of MORHAN. This video invites all people, but especially healthcare workers, to recognize the knowledge held by persons affected by Hansen’s disease and to change the way affected people, their lives and the disease are regarded. Narrated in Portuguese, the video is subtitled in English with translation by Carlos Abelheira.



And have you watched the webdocumentary **From the draft to law in action - Principles and Guidelines for the elimination of discrimination against persons affected by leprosy and their family members**? The video tells a bit of the story behind the elaboration of the Draft set of principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members, and brings together testimonies from persons affected by Hansen’s disease and their family members from different parts of the world.



Watch the full webdocumentary of the UN Special Rapporteur Alice Cruz mandate, with the testimony of Mangala and many others at:

<https://bit.ly/FromTheDraftToLawInAction>

Stay tuned!

The Leprosy Mission International recently launched its first newsletter, check it out:

[TLM INTERNATIONAL NEWS](#)



Organizations of persons affected by Hansen’s disease and other key stakeholders also produce newsletters and bulletins, follow those to stay well informed:



[WHO GOODWILL AMBASSADOR FOR LEPROSY ELIMINATION](#)



[APAL-INDIA](#)



[ILEP](#)



[MORHAN/BRAZIL](#)



[GPZL](#)



Final Notes

I say good-bye with the hope that 2022 can be a turning point and that many of the fundamental activities of my mandate can be resumed, such as visits to countries. Moreover, I hope many of us can meet in person at the next 21st International Leprosy Congress to be held in India in November, 2022.

Alice Cruz

UN SPECIAL RAPPORTEUR ON THE ELIMINATION OF DISCRIMINATION AGAINST PERSONS AFFECTED BY LEPROSY AND THEIR FAMILY MEMBERS

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